

# Strengthening the Process of Informed Consent to Address Racial and Ethnic Disparities in Health Care and Research

**Monday, June 28, 2004**

**8:30 a.m. - 12:00 p.m. (Central Time)**

The U.S. Department of Health and Human Services (HHS) is sponsoring a two-day conference in Tuskegee, Alabama to examine how the process, principals, and application of "informed consent" in research and health care might be strengthened and/or expanded. The goal of this conference is to protect and promote a "culture of trust" between health researchers and research volunteers, between healthcare providers and patients, and between research institutions/healthcare organizations and communities at-large from which prospective research subjects and/or patients originate.

The first phase of this project, comprised of "data gathering" activities has been completed. The second phase of this project involves the convening of an invitational conference whose purpose is as follows:

To engage national leaders across the health care/health research spectrum on these issues.

To highlight current and emerging research and related efforts to illuminate understanding of and solutions to the issues at hand.

To showcase promising practices, models that work and lessons learned.

The HHS is providing, via satellite broadcast, select portions of Monday's presentation as listed below.

## **Tentative Agenda:**

\*Times are approximate

**8:30 - 9:00 a.m.**

**Stephen Olufemi Sodeke, MSc, PhD**  
Interim Director, National Center for Bioethics in  
Research and Healthcare  
Tuskegee University

### **Welcome to Tuskegee**

**Benjamin F. Payton, PhD**  
President, Tuskegee University

### **U.S. Department of Health and Human Services' Role in Addressing Racial and Ethnic Health Disparities**

**The Honorable Claude A. Allen**  
Deputy Secretary  
U.S. Department of Health and Human Services

**9:00 - 9:15 a.m.**

### **Draft Report: Strengthening the Informed Consent Process to Address Racial and Ethnic Disparities in Health Care & Research**

**Ruth T. Peror, MPA**  
Executive Director  
Summit Health Institute for Research and  
Education (SHIRE)

**9:15 - 10:15 a.m.**

### **The Tuskegee Syphilis Experiment: Remembering the Past, Acknowledging its Impact on the Present, Moving Towards a Better Future**

**James H. Jones, PhD**  
Social Historian and Author

**10:30 - 11:15 a.m.**

### **The History and Evolution of Informed Consent in Research and Health Care**

**Edward F. Gabriele, DMin**  
Director, Office of Professional Integrity & Ethics  
Bureau of Medicine and Surgery  
Department of the Navy

**11:15 a.m. - 12:00 p.m.**

### **Using Evidence to Improve the Informed Consent Process in Research & Health Care**

**Jeremy Sugarman, MD, MPH, MA**  
Harvey M. Meyerhoff, Professor of Bioethics  
Phoebe R. Berman, Bioethics Institute  
Johns Hopkins University

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## **Satellite Broadcast Details:**

Registration: [www.adph.org/alphntn](http://www.adph.org/alphntn)

No handout materials are available.

No contact hours/CEU's are available.

Cost: No cost to view

Satellite Coordinates: C & Ku Band

Questions: [alphntn@adph.state.al.us](mailto:alphntn@adph.state.al.us) or 334-206-5618

**Sponsored by the U.S. Department of Health & Human Services (HHS)  
Satellite broadcast of conference proceedings provided by the Alabama Department of Public Health**